

# LOOMING HOUSING CRISIS FOR VULNERABLE ADULTS

The lack of options for providing homes for adults with developmental and high, complex needs is already dire, and is about to get much worse.

## KEY LESSONS

- Adults with developmental disabilities and *high, complex needs* are a distinct group with distinct concerns
- Members of this group (and their caregivers) are facing a crisis, if they're not in crisis already
- Their crisis is part of the general lack of suitable homes for people with disabilities, but *more complicated, and not addressed by current programs*
- A recent study identifies two initial steps: (a) provide clearer and more accessible information about existing housing options; (b) increased funding with fewer strings to allow people to pursue creative housing options

## IMAGINE

Imagine you are 80 years old, and the primary caregiver of your 55-year-old son who has developmental disabilities and high, complex needs.<sup>i</sup> Together with your spouse, the three of you live in the Waterloo Region on a fixed income. You are aging, managing your own health issues, and experiencing exhaustion from providing support for your son 24/7. You support your son through frequent seizures and anxiety attacks, as well as living with disrupted sleep due to getting up at night for his toileting needs. This situation is almost unsustainable, yet your search for other options yields nothing. You would like your son to live nearby where he can remain closely involved with family and you can have peace of mind for his future. But a single bedroom apartment – even *before* living expenses – will cost roughly \$16 000 annually.<sup>ii</sup> Subsidized housing isn't an option, due to the eligibility requirements: one resident of subsidized housing must be able to live independently.<sup>iii</sup> And that's just the living space. There is the 24/7 individualized support required to meet your son's high, complex needs to consider. This support inevitably must include paid professionals. Planning and paying for social support, health care, personal care, and nutrition support is part of any suitable living arrangement. Your son has some government funding,<sup>iv</sup> but it comes with strings attached. And however carefully you budget, the funding he can use won't cover the costs of support he needs. Your family is one injury or health complication away from a crisis.

At first glance, this looks like a familiar problem. Ombudsman Paul Dubé's report released in August 2016, entitled *Nowhere to Turn*, amply displayed that many individuals with developmental disabilities and their families are going into crisis over lack of housing options.<sup>v</sup> But people with developmental disabilities *and high, complex needs* are members of a distinct group who's housing needs are more complicated, and not addressed by current programs. A recent study<sup>vi</sup> initiated by Waterloo Wellington Autism Services and carried out in partnership with researchers at the University of Waterloo, provides insight into the current situations, and the unique housing needs, of this group.<sup>vii</sup>

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*“The emotional stress around what does the future hold for [them]... the emotional stress is costly.”*

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## A DISTINCT GROUP WITH DISTINCT NEEDS

People with developmental disabilities and high complex needs are a distinct group with distinct challenges in finding suitable homes. The study found evidence that both these individuals and those who care for them recognize *high, complex needs*, summarized as needing individualized support, including proactive monitoring, that is “within arm’s reach” 24/7, as an apt characterization of their situation and as the key factor determining the support they require. Obviously, for members of this group any suitable home must include this 24/7 individualized support, including personal care activities (bathing, dressing, grooming, mouth care, toileting, transferring bed/chair, walking, climbing stairs, and eating). Securing an affordable living space is only part of the task.

## THE SITUATION IS URGENT

The study shows that for adults with developmental disabilities and high, complex needs the lack of housing is an urgent situation. The majority of caregivers stated that the adult with developmental disabilities and high, complex needs, will need a change of living arrangements. The reason for this change? They as caregivers are “ageing/exhausted/will be unable to continue” providing care. Most caregivers in the study are parents providing care at home for their son or daughter. While recognizing the unsustainability of this arrangement as they age and become exhausted, they also see no feasible alternatives. They are one injury or health complication away from a crisis, and in a situation that is a recipe for despair.

## WHAT DO PEOPLE WANT?

Almost all participants would be willing to consider a shared living arrangement, often to avoid loneliness but also because it seems more financially plausible. Would it therefore be enough to build more group homes? Some caregivers said, often along with a comment that out of desperation and not knowing of any other options, that they hadn’t thought beyond group homes. Others said they would find a group home acceptable, *but only under the conditions that the support provided is genuinely caring, and that residents have more choices and individualization of activities than has been available in most existing group homes.*

Still others find existing group homes very problematic, and feel pushed to create their own housing options. Pursuing such options is seen both as a way to match homes to individual needs and to create models that others can learn from. But being *willing* to pursue creative housing options and being *able* to do so are entirely different. Even when families want to pursue innovative housing options, there are many barriers, especially financial ones. Funding rules that make it difficult to create *shared* living arrangements *different from* traditional group homes are a particular source of frustration. More flexible rules, information about options, and funding with fewer strings attached, would make pursuing creative options possible.

## THE COST OF UNCERTAINTY

Caregivers consistently stressed the total lack of feasible housing options. This uncertainty comes with a high cost. It translates into additional stress on the caregiver and the adult, right now. As one Caregiver noted, “...it’s still that uncertain future that can really weigh parents down.” And another: “I know there’s the piece of worry that we carry. The emotional stress around what does the future hold for [them] and us and the whole living situation piece. I think the emotional stress is costly.”

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<sup>i</sup> In the study, *high, complex needs* is defined as: A person has high, complex needs if, as a result of health (including mental health) and neuro-developmental disorders and social and communication challenges, they need 24/7 support where support is “never more than arms-length” away. For some people at all times and for some people at some times, this is a need for continual and proactive support – that is, the person needs support to be constantly at the ready, e.g., the person cannot be left alone in a house, even for a short time, and they require a range of proactive and ongoing attentive support for themselves and managing their environment (See §4).

<sup>ii</sup> According to RentBoard.ca, the current average price of a 1-bedroom apartment in Waterloo region is \$1324/monthly (October 2020).

<sup>iii</sup> Affordable housing requires one resident to be able live independently “with or without support services” *DSO Housing Toolkit*.

<sup>iv</sup> “Passport” funding from Developmental Services Ontario offers individuals with a developmental disability diagnosis *up to* \$35 000 a year but the average allocation of funds is closer to \$10 000 a year of reimbursement funds, however, one is not permitted to use their Passport funding for housing costs, among other restrictions. Most likely, an adult receives \$900-1000 of income a month from Ontario Disability Services Program (ODSP), dedicated to living expenses such as prescriptions, vision care, and community support.

<sup>v</sup> Paul Dubé’s report highlights 18 cases of adults with developmental disabilities who were left homeless, abused, abandoned, or inappropriately housed in hospitals, long-term care facilities, and jails. Paul Dubé, *Nowhere to Turn*, 2016.

<sup>vi</sup> This research was carried out prior to the vast changes brought about by the COVID-19 pandemic. We acknowledge that had this research taken place after March 2020, participants of the surveys and interviews may have said things differently, as the pandemic has changed so much of daily life. The barriers people face to achieving housing solutions highlighted in the report (e.g., financial barriers, lack of available and qualified personal support workers) have likely been exacerbated.

<sup>vii</sup> The study focused on a particular geographical region of Ontario (the Central West Region). This geographic focus is motivated by the practical constraints of the study, namely the time and funding available, and the location of the funding organization and the researchers. While we suspect that the results described below would be similar for other regions, some caution is of course warranted in making such generalizations.